

## **Testimony on Raised Bill 1088:**

### **An Act Concerning Services for Individuals with Intellectual Disability**

Chairpersons Gerratana and Ritter and members of the Public Health Committee my name is Patrick Vingo. I am a member of the Council on Developmental Services and vice president of Parents & Friends of Lower Fairfield Center (LFC) a publically operated ICF/IDD Regional Center in the Silvermine neighborhood of Norwalk.

My sister Marta was born with cerebral palsy and a profound level of disability. She was a resident of LFC for 14 years until her death at age 53. For the first 39 years of her life she lived at home with her four brothers and parents. Needing round the clock care for eating, dressing, bathing, grooming, all of the necessities of living was a full time round the clock commitment for our parents. In 1994 that role turned to the dedicated staff of LFC with much involvement of our family when Marta moved in as a resident there.

I wish to express my concerns over the scope and intent of raised bill #1088; an Act Concerning Services for Individuals with Intellectual disability.

While we believe all individuals with intellectual disabilities can and must live as independently as possible it must be pointed out that some people with severe physical as well as intellectual disabilities require 24 hour onsite nursing and concentration of therapeutic services that an ICF/IDD campus setting provides. The people I speak of are the medically delicate for which regional centers offer the best integrated care and delivery of supports. Beneficially, ICF facilities are subject to Department of Health inspections insuring that another set of eyes is overseeing the best standards of health and safety. This is something that is not provided in privately operated community based settings.

The assault on congregate settings has been vociferous at times but where a person lays their head to sleep at night does not determine their inclusion into a community. An active and thorough personal care plan does. No philosophy or budgeting demands will make the care of individuals with an extremely high level of need (LON) inexpensive. No matter where they live supports and services will be intensive.

Particularly onerous is this bill's coupling of the Messier v. Southbury Training School decision to the regional centers. Lower Fairfield Center nor any of the other ICF regional centers were ever in violation of the law or subject to this legal action. The attaching of the Messier decision to them is guilt by association and unjustified.

We at Parents & Friends share a vision of integration into community based settings as well. However, it does not include eliminating the comprehensive care for that smaller part of the population with severe physical and intellectual disabilities who receive on site nursing and therapeutic supports. If these things could be provided in a setting other than an ICF/IDD we would be in accord.

Bill 1088 ties the hands for people seeking the best options for their children and is analogous to restricting Medicaid support to senior citizens who choose to live in assisted living facilities and not in single family homes. As such 1088 closes the door on a range of options for a segment of the population that needs it the most. We are not willing to experiment with our children and siblings to satisfy a philosophy and/or budgetary pressures.

I urge you to reconsider the wording, intent and scope of proposed act 1088 to provide for the best practices of comprehensive care for the severely disabled amongst us.

Thank you,

